

Members:

Rep. Vanessa Summers, Chair
Rep. Markt Lytle
Rep. Robert Alderman
Rep. Cleo Duncan
Sen. Richard Worman
Sen. Kent Adams
Sen. Allie Craycraft
Sen. Joseph O'Day



Lay Members:

Hugh Beebe
Capt. Michael Carmin
Nan Daley
Donna Ott
Herbert Grulke
Becky Zaseck

COMMISSION ON AUTISM

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MEETING MINUTES

Meeting Date: June 24, 1998
Meeting Time: 1:30 P.M.
Meeting Place: State House, 200 W. Washington St., Room 125
Meeting City: Indianapolis, Indiana
Meeting Number: 1

Members Present: Rep. Vanessa Summers, Chairperson; Rep. Robert Alderman; Rep. Cleo Duncan; Sen. Richard Worman; Sen. Kent Adams; Sen. Allie Craycraft; Sen. Joseph O'Day; Capt. Michael Carmin; Nan Daley; Donna Ott; Herbert Grulke.

Members Absent: Rep. Markt Lytle; Hugh Beebe; Becky Zaseck.

Representative Vanessa Summers, chair of the Commission, called the meeting to order at 1:40 and asked the members and the audience to introduce themselves.

DISCUSSION OF SB 148-1998 AND AUTISM WAIVER WAITING LIST

Representative Summers asked for discussion of last year's legislation which changed the model waiver to a regular waiver (SB 148), and the status of the autism waiver waiting list. Korryn Fairman, a supervisor with the Indiana Family and Social Services Administration's Office of Medicaid Policy and Planning provided an update on the status of the autism waiver. Ms. Fairman indicated that there are 145 current slots which will increase to 200 on July 1, 1998 and that an additional 200 slots can be added over five years contingent on an additional financial commitment by the State. The state of the waiver is such that the additional slots have been approved in advance of the receipt of funds. This approach was taken in order to avoid the waiting period that would occur if FSSA waited for the State to provide more dollars and then had to apply with the federal government for the additional slots. Ms. Fairman stated that as of the date of the meeting, the waiver consisted of 145 slots.

Mr. Grulke indicated that there were 99 active cases on the waiver and questioned why all 145 slots weren't filled, when the waiting list is currently 463. Ms. Fairman was unable to explain the delay, but reported that 106 slots were active, and 502 were on the waiting list.

Representative Summers expressed dismay at the delay and recalled that during last year's interim, the Commission requested that FSSA do all preliminary work necessary in order to place more people on the waiver quickly once the additional slots became available. She concluded that FSSA had not completed that work as requested. Ms. Fairman responded that it might be helpful for Mr. Walter Thomas to speak

to the Commission regarding active vs. available slots.

Representing the Indiana Resource Center for Autism, Ms. Kathy Pratt and Mr. Scott Bellini presented the preliminary results of a survey conducted to gauge the level of satisfaction with and effectiveness of the current Medicaid Waiver system among families and individuals with autism.¹ Based on partial data of 200 responses analyzed to date, families expressed frustration with a variety of issues including: the length of the waiting list; problems with bureaucracy; difficulty in finding and retaining consistent, trained respite care providers, and denial of insurance coverage.² However, families expressed gratitude for the waiver, and those on the waiting list indicated a desire to be updated every six months as to their place on the list. The majority of families are using the Intermediate Care Facility /Mental Retardation (ICFMR) waiver instead of the autism waiver. Ms. Pratt stressed the importance of promoting the availability of the waiver to families. She requested and quickly received a good packet from the Governor's Planning Council, and also requested information from FSSA four weeks ago but has yet to receive any response. Ms. Daley also expressed concern about the lack of information readily accessible to families.

DISCUSSION CONCERNING CARE PROVIDERS

Ms. Daley commented on the problems families experience with respite care providers. Often these providers experience a high staff turnover rate. Ms. Daley cited examples of families which had numerous respite care providers in and out of their home, leaving the children with little structure or consistency of care. It was indicated that lack of training and low pay are largely responsible for the high turnover (for example, many respite care providers pay employees \$6 per hour and do not pay mileage, but are charging Medicaid a much higher hourly rate). Ms. Daley asked if some form of a voucher system, allowing families to choose providers directly, would be a better way to provide better and more cost-effective service. Ms. Daley stated a desire to have families come in and testify before the Commission about their experiences with providers and the autism waiver. In response to Ms. Daley's concerns, Ms. Fairman reported that the Medicaid Office has approved an rate increase for respite care but that the Budget Agency has yet to approve it. However, Ms. Fairman speculated that a rate increase would not guarantee better service, and may only increase the profits of providers.

Representative Summers requested a list of providers that serve autistic clients, so that the Commission can seek their testimony. Mr. Grulke estimated that approximately 300 providers serve autistic clients, and that some providers do give employees good training, which is a crucial requirement for good service. Some difficulties which providers face include the inability to provide enough hourly work to give employees full time status and benefits, and the inability to compete for good employees in a tight labor market. Mr. Grulke also reminded the Commission that case managers spread respite care work among many providers rather than giving all of the work to the best providers, and that each family often ends up with several providers.

Ms. Fairman explained that federal requirements for waivers include the freedom of parents to choose their providers, and that putting more people on the waiver will result in pushing bad providers out of the market. She also stressed that a major concern is the lack of quality assurance provided by the state, and suggested that the creation of a toll-free number for families to report complaints would be helpful. Mr. Grulke agreed with the need for quality assurance and felt that without it, the state has no way to determine whether services are good or bad, and no opportunity to resolve problems when they occur.

DISCUSSION OF GROUP HOMES

¹ A copy of the Indiana Resource Center for Autism's introductory letter to families is on file in the Legislative Information Center, Room 230 of the State House, Indianapolis, Indiana, 46204. The telephone number of the Legislative Information Center is (317) 232-9856.

² A copy of the preliminary results of the autism waiver survey compiled by the Indiana Resource Center for Autism is on file in the Legislative Information Center (see footnote 1).

Representative Summers reiterated her desire to have providers testify before the Commission, and also discussed the issue of group homes for people with autism. Mr. Grulke mentioned that a bill was enacted in 1997 to provide an emergency fund for families in crisis, but at the same time, all other residential supports are frozen, and the waiting lists are longer than ever before.

Sen. Worman asked whether there are any plans to expand the number of group homes in the state. According to Mr. Grulke, the state has only added one adult group home and none for children in the last five years. Mr. Grulke stated that there have been no evaluations conducted to determine the current need for residential services, and that to his knowledge, no openings exist in any of the adult group homes, so when children grow up and can no longer stay in a children's group home, they have nowhere to go.

Rep. Summers stated that she would like FSSA to explain the moratorium on new group homes to the Commission. Sen. Worman agreed that FSSA should testify and update the Commission on their progress for residential services. Ms. Pratt told the Commission of the existence of a "317 Task Force" established by the MRDD Commission to investigate the current state of residential services. The Task Force's report should be ready in late July. Ms. Pratt wondered if it would be possible to have a joint meeting with MRDD to hear the results of the report.

DISCUSSION CONCERNING FUTURE COMMISSION ACTIVITY

Representative Summers stated that she would like Mr. Walter Thomas, Director of FSSA's Waiver Unit to update the Commission on the status of the waiting list. Representative Summers also stated that she would like the Commission to attempt to address the denial of insurance coverage to families with autism despite HB 1081-1997 which defined autism as a neurological disorder. Senator Worman offered to investigate any specific case using his experience with the insurance industry. Ms. Pratt indicated that Kentucky enacted legislation providing insurance coverage to people with autism, but in many states autism is considered a psychiatric condition for insurance purposes. Ms. Pratt also suggested that Janet Schadee from the Indiana Department of Health testify regarding the Indiana Children's Special Health Care Services (CSHCS) program. The rules for eligibility for the CSHCS program do not include autism because the Diagnostic and Statistical Manual of Mental Disorders lists autism as a psychiatric condition, and as a result, the CSHCS program does not cover the disorder.³

Senator Craycraft expressed an interest in requesting a representative from the insurance industry to speak to the Commission about the issue of coverage for people with autism. Senator Worman advised that the Commission investigate the state's insurance plans to determine whether they provide coverage for autism. He reiterated his willingness to research specific cases in which families are denied insurance coverage, and commented that it is unlikely that denial of coverage for a brand new risk due to a pre-existing condition can be stopped, but that the state plan (ICHIA) does cover individuals who are denied coverage due to pre-existing conditions.

Representative Summers set the Commission's second meeting for July 22, 1998, and stated that she would like the agenda to include an update from Mr. Thomas, testimony on waiver services from parents of children with autism, and Ms. Schadee from the Department of Health. The August meeting will bring FSSA in to inform the Commission of their planning for group homes. In September a joint meeting will be held with the MRDD Commission to hear the report from the "317 Task Force". Representative Summers also would like to include insurance representatives and providers of services to people with autism on the agenda at some point during the interim session.

Before closing the meeting, Representative Summers asked for comments from the Commission. Representative Duncan asked whether the legislation changing the definition of autism supersedes the authority of the insurance industry to deny coverage to people with autism. Ann Naughton, LSA Staff Attorney for the Commission, explained that for it to apply to insurance coverage, the new definition would

³Copies of both the "Special Care for Children with Special Needs" pamphlet produced by the Indiana State Department of Health, and an article entitled "CSHCS and Autism" produced by the Department of Health and Human Services are on file in the Legislative Information Center (see footnote 1).

have to be placed in the insurance section of the Indiana Code. Ms. Daley expressed concern about the lack of educational opportunities for autistic children when the school year ends. She reported that in her experience, extended year services are not provided by the Department of Special Education although her understanding is that the Department is required to provide such services. Representative Alderman requested that LSA determine an estimated cost of the provision of such services, before taking any action.

Representative Summers announced that the next meeting would take place on July 22, 1998 at 1:30 p.m. There being no further business to come before the Commission, Representative Summers adjourned the meeting at approximately 2:50 p.m.